Children's Renal & Urology Unit
Nottingham Children’s Hospital
CHILDREN’S RENAL & UROLOGY UNIT

ANNUAL REPORT 2011

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Report compiled by:  Dr Martin Christian
Typed by: Judith Hayes

Front Cover: Four Seasons displayed on corridor alongside Ward E17
commissioned by Kinder Fund and painted by Kirsty Whitrow
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MISSION STATEMENT

We will
a) Strive for excellence in the care of all children with acute and chronic renal and urological problems

b) Embrace a partnership ideal with the families and be sensitive to multiculturism

c) Improve and develop all means of communication with children and their carers and ensure meaningful patient and family involvement

d) Educate all staff and professionals in contact with children with renal problems, including those outside the hospital such as general practitioners, school and nursery staff

f) Seek to carry out research on clinical care and implement new scientific knowledge to maintain the unit at the leading edge of paediatric renal and urology care

Adopted in 1991 for First Annual Report
SUMMARY

It has now been four years since we moved round the Nottingham ring road to our new home at the QMC campus. In that time, we have moved from being part of children’s services to part of Nottingham Children’s Hospital. It’s possible to tell that you’re in the Children’s Hospital as you walk around QMC by the bright rainbow flashings to the floor coverings, which is how it should be – an environment that does what it can to make hospital more friendly and accessible for the children it treats. In the Renal and Urology Unit, we’ve done our bit to brighten corridors with the beautiful season pictures and Goose Fair murals that have been commissioned by the Kinder Appeal and painted by local artist Kirsty Whitrow. They can be seen in the corridor alongside ward E17, making it very clear to patients or relatives straying from the adult vascular wards that they are now in the Children’s Hospital!

Four years has brought a sense of settling in manifested in an acceptance of those things we wanted to improve but which we have been unable to change quickly. High up on the list of those things is the lack of adequate facilities for day-case or ward attender patients. It is important at this point that an acceptance mindset is not one of resignation but translates into constructive working with others within the Children’s Hospital to improve day-care facilities for all. And that is what we have been trying to do over this last year, working with the Better for You project. It is accepted that there is a need for day-case facilities for the renal and urology service. We hope to have a cost-neutral project, funded charitably and a day-case unit that is located adjacent to the ward and haemodialysis unit such that it can also be staffing-neutral, thus meeting another criterion. I hope there will be more concrete news to report in next year’s annual report.

2011 was a challenging year though with many things to be thankful for too. The financial climate in both direct and indirect ways has impacted upon the service. We have lost key members of staff who have been replaced only partially or not at all. Through Trust workforce change, Dot MacKinlay took early retirement in the summer of 2011. Dot worked for many years within paediatric nephrology and we are indebted to her for many improvements to our understanding and management of the psychosocial aspects of chronic kidney disease, in recent times, most notably for her work on helping children prepare for painful procedures and on measuring quality of life for children with chronic kidney disease. Using a validated tool which Dot helped to develop with Jacqueline Collier, she showed that self-reported quality of life for children with chronic kidney disease is no different to healthy children, leading to further on-going work to explore the reasons for this. Dot’s replacement is not a full-time position but we have been pleased to welcome Dr Rohan Naidoo and are encouraged by his enthusiasm for the need for psychological input to our service. His commitment to the renal team is limited by the additional demands on his half-time post from other paediatric services.

At the end of 2011, through a re-organisation of administration/clerical posts within the Children’s Hospital, two experienced secretaries, Ann Johnson and Barbara Wiklo, moved to other paediatric services. We have been pleased to welcome other secretaries within our team: Sandie McLauchlan whose support of the urology service is now linked closer to nephrology, Pauline Leivers sharing responsibility for rheumatology and nephrology, and Pam Greenbank. The administration workload is considerable, borne out by the long delays in clinic letter typing (just one of the many differing administrative roles expected of secretaries) that we still have to address and we continue to monitor the situation closely.

On a more positive note, in May 2011 we were able to transfer the contracts of our two social workers from Nottingham City Council to Nottingham University Hospitals NHS
Trust, with the shortfall in funding supported by a 3-year grant from the British Kidney Patient Association (BKPA). A year in and a unique system of including social workers in a health department with externally-commissioned professional supervision is working well and being shared with other paediatric renal social workers as an example of good practice.

We are also thankful to the BKPA for agreeing to continue funding for a renal youth work development post which has not only enabled us to retain the skills of Dorro Hackett and her important contribution to supporting our young people but as the post funded is a full-time one, it enables us to develop the youth work in new ways. The qualities of another of our team have been recognised: Claire Hardy, play specialist, was short-listed for an NUH diamond award and although the Family Health winner was the Paediatric Emergency Pathway Team, the hard work of Claire was appropriately acknowledged.

We have continued to develop the transition work. The transition residential is now firmly a part of the calendar. We have also made closer links with young adult work at Sheffield. For patients transferring to both Nottingham and Sheffield, we now have a transition clinic (in the true sense of a clinic with both adult and paediatric nephrologists where they are not simply transferred but can return to be seen) and a twice yearly multi-disciplinary meeting to discuss patients in the transition phase.

We have continued to meet standards in terms of infective complications of patients on dialysis. Our transplant numbers have exceeded what we anticipated would be our largest number of transplant patients in a year for some time and it is good to see some pressure taken off what was a record number of children on dialysis for our unit. By the middle of 2012, signs are that large numbers of children being transplanted is not continuing but dialysis and in particular haemodialysis numbers have begun to increase again.

In 2012 we are due to benefit from a new ICT package for renal services. Away from the City Hospital we have found that local hospital ICT packages for blood results are easier to access but this new package will provide much more comprehensive support that will allow us to enter details of dialysis prescriptions, dietetic input and social work support. Clinic letters can be generated from bespoke templates and once up and running we hope this will become an electronic patient record for our chronic renal patients and take some of the pressure off administrative staff.

There are possibilities to be able to import lab data into the programme from other hospitals and this offers opportunities to develop the network outreach work. The RCPCH’s document on paediatric nephrology networks endorses much that we have been doing to develop and formalise our network. The direction of commissioning paediatric nephrology services is currently being discussed nationally and we expect to see further developments here soon.

Martin Christian
Lead Consultant, August 2012
## STAFF AND FACILITIES

<table>
<thead>
<tr>
<th><strong>Medical Staff</strong></th>
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</thead>
</table>
| **Consultant Paediatric Nephrologists** | Dr Jonathan Evans (Clinical Director, Family Health & 0.6 WTE clinical)  
Dr Farida Hussain (maternity leave April 2011 to March 2012)  
Dr Martin Christian  
Dr Meeta Mallik  
Dr Andrew Lunn  
Dr Corinne Langstaff (PT locum consultant May 2011 to June 2012) |
| **National Grid Trainee** | Dr Wesley Hayes |
| **ST 2/3 Trainee** | Rotates every 6 months |
| **F2 Trainee** | Rotates every 4 months |
| **Paediatric Urologists** | Mr Manoj Shenoy  
Mr Alun Williams  
Mrs Nia Fraser |
| **Surgical Trainee** | Rotates every 6 months |
| **Surgical SHO** | Rotates every 3 months |
| **Transplant Surgeons** | Mr Keith Rigg  
Mr Alun Williams  
Mr Shantanu Bhattacharjya  
Mrs Amanda Knight  
Mr Owen Cole (urologist) |
| **Radiologists** | Dr Nigel Broderick  
Dr John Somers  
Dr Kath Halliday |
| **Pathologists** | Dr Tom McCulloch  
Dr Zsolt Hodi |

The nephrology service remains a **CONSULTANT DELIVERED SERVICE** as all middle grade and junior staff participate in general paediatric on call rota.

### Nursing Team

<table>
<thead>
<tr>
<th>Nurse/Role</th>
<th>Position</th>
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<tbody>
<tr>
<td>Shelley Jepson</td>
<td>Senior Paediatric Nephrology Nurse</td>
</tr>
<tr>
<td>Roy Connell</td>
<td>Clinical Nurse Specialist – Dialysis</td>
</tr>
<tr>
<td>Kim Helm</td>
<td>Clinical Nurse Specialist – Transplant</td>
</tr>
<tr>
<td>Kate Baker</td>
<td>Renal Nurse – Transplant (0.7 WTE)</td>
</tr>
<tr>
<td>Sharon Mould</td>
<td>Dialysis Nurse (0.8 WTE)</td>
</tr>
<tr>
<td>Gillian Elwood</td>
<td>Nephrology Liaison Nurse (0.9 WTE)</td>
</tr>
<tr>
<td>Diane Blyton</td>
<td>Renal Nurse Educator</td>
</tr>
<tr>
<td>Chris Rhodes</td>
<td>Urology Nurse Specialist (0.6 WTE)</td>
</tr>
<tr>
<td>Gill Young</td>
<td>Urology Nurse</td>
</tr>
<tr>
<td>Emma Stockdale</td>
<td>Urology Nurse</td>
</tr>
<tr>
<td>Caroline Ward</td>
<td>Urology Nurse</td>
</tr>
<tr>
<td>Molly McLaughlin</td>
<td>Renal Critical Care Nurse</td>
</tr>
<tr>
<td>Ian Buchan</td>
<td>Junior Charge Nurse</td>
</tr>
<tr>
<td>David Cooper</td>
<td>Junior Charge Nurse – Haemodialysis</td>
</tr>
<tr>
<td>Michelle Kirkland</td>
<td>Ward Manager (0.8 WTE)</td>
</tr>
</tbody>
</table>
The Children's Clinic
The clinic is run by June Nicholson. We said farewell to Pip Waddington who retired early on health grounds last year after many years of service.

Dietetics
Pearl Pugh (0.6 WTE, maternity leave December 2011 to August 2012) and Emma Kelly (1.0 WTE) are our paediatric renal dietitians. During Pearl’s maternity leave, Emma has been support by Victoria Donovan, dietetic assistant.

Social Work
Paediatric Renal Social Workers are Heidi Steward (FT) and Suzanne Batte (PT) whose contracts have been transferred from Nottingham City Council to NUH, with top-up financial support from the BKPA.

Psychologist
Dorothy MacKinlay retired in July 2011 after many years supporting the psychosocial needs and developing extensive research into quality of life for children with chronic kidney disease. Dr Rohan Naidoo (0.5 WTE) provides psychological input to all speciality areas within the Children’s Hospital.

School Teachers
Kate Lawes and John Young are the schoolteachers on the Dialysis Unit and Ward E17. They are greatly assisted on the Dialysis Unit by 2 Teaching Assistants, Jonathan Gray and Denise Cross. They are also helped once a week by a volunteer, Janet Wilson. Elaine Boon retired in 2011.

Play Specialist
Claire Hardy

Youth Worker
Dorro Hackett has increased her hours to become a full-time renal youth development worker. This post is funded by the BKPA for 3 years. She is supported by Donna Hilton who manages youth and play services for the children’s hospital. Children and young people within the Renal and Urology Unit also benefit from support from the other Children’s Hospital Youth Workers and volunteers.

Family Care Coordinator
Denise Martin continues to provide support to our families.

Administrative and Secretarial Staff
Judith Hayes, Sandie McLauchlan, Pauline Leivers and Pam Greenbank provide invaluable senior administrative support. They are supported by a team of filing clerks. Ann Johnson and Barbara Wiklo have been redeployed to other teams within the Children’s Hospital as part of an extensive administrative and clerical review. Lynn Brand helps in data collection as the ward receptionist.

Housekeeping
Ann, Janet and Val endeavour to maintain high standards on the ward.

Technical Support
The excellent support from the renal unit technical staff for the running of the dialysis machines is very much appreciated and Paula Conway for administration of supplies.
Transplant Coordinators
Richard Bowen leads the team of recipient co-ordinators. Anne Theakstone and Karen Stopper are the live donor co-ordinators.

Renal Pharmacist
Andrew Wignell provides pharmacy support

Volunteers
Pat, Pauline and Denise provide invaluable support on the ward and in clinic.

Chaplaincy Support
Rev Anne Ladd joined the chaplaincy team in 2011 with a particular remit for the Children’s Hospital.

Management
Julia Scrine and Sandra Minich are Business and Assistant Business Managers respectively. Dr Stephanie Smith is the Children’s Hospital Lead and Dr Tabitha Randell is the Lead for Paediatric Specialties. Angela Horsley is Clinical Lead for Children’s Services and Sally Shearer is Matron for Children's Services.
WARD ACTIVITY

Inpatient facilities: 10-bedded ward with 4 en-suite side rooms. One side room and beds in the 2-bedded bay are plumbed to allow haemodialysis at the bedside. The ward also contains a treatment room, a playroom, small schoolroom and a parents’ sitting room.

Adjacent to the ward is the Elizabeth Ward Dialysis Unit, a 7-station haemodialysis unit including one isolation cubicle. At the dialysis unit end of the ward is a multi-purpose room suitable for interviewing families, training in peritoneal dialysis or hosting small meetings.

Pressure on in-patient beds has again been felt in 2011. E17 ward also accepts general paediatric patients and patients from other specialties when there are shortages of beds elsewhere in the Children’s Hospital. When there is bed pressure it is rare to have problems in accommodating renal patients from the region that need a specialist bed.

The rise in ward out-patient activity has been sustained throughout 2011. Discussion about day-case facilities is on-going. There are currently ring-fenced funds within our charitable account to support the development of a day-case unit adjacent to the ward primarily for nephrology and urology patients. This would take considerable pressure off the ward and in particular the ward treatment room.
RENAL BIOPSIES

We attempt to do renal biopsies as a daycase procedure whenever possible. A total of 111 biopsies were performed in 2011 (116 in 2010), of which 66 were native (diagnostic) biopsies and 45 were transplant biopsies. These figures for the last 3 years are shown graphically in the figure.

We rely heavily on the excellent play preparation and support during the procedure provided by our play specialists. Parents are given the option to stay with their child during the procedure which is performed in the treatment room on the ward with ultrasound localisation of the kidneys and in most cases now, real-time ultrasound guidance.

In 2012 we have agreed to co-ordinate once again a national audit of renal biopsies in children, assessing adequacy and complications.

Clinico-pathological meetings to review renal biopsies are held monthly with Dr Tom McCulloch and Dr Zsolt Hodi, Consultant Histopathologists. The renal histopathology service has now re-located to the QMC Campus but the consultant pathologists remain based at the City Hospital Campus. Same-day provisional verbal reporting is available for biopsies that are carried out in the mornings during the working week. From 2012 there is an on-call service on Saturdays and bank holidays.

Referral centres for native diagnostic biopsies in 2011 with figures for 2010 in parentheses (n = 66):

- Nottingham 9 (9)
- Cambridge 2 (4)
- Kings Lynn 1 (0)
- Barnsley 3 (3)
- Kettering 2 (2)
- Derby 4 (7)
- Norwich 6 (6)
- Kings Mill 1 (4)
- Sheffield 7 (7)
- West Suffolk 1 (2)
- Leicester 6 (5)
- Chesterfield 1 (3)
- Peterborough 8 (6)
- Hinchingbrooke 0 (0)
- Grimsby 0 (1)
- Boston 0 (0)
- Doncaster 5 (2)
- Rotherham 4 (4)
- Lincoln 3 (4)
- Bassetlaw 0 (1)
OUTPATIENT ACTIVITY IN NOTTINGHAM

Outpatient nephrology clinics in Nottingham comprise up to four general nephrology clinics per week held on Monday afternoons (Dr Hussain), Tuesday mornings (Dr Mallik) and Wednesday mornings (Dr Christian and Dr Lunn). Clinics do not happen when the relevant consultant is on-service to allow them adequate space to manage issues with ward patients. Monday afternoon and Wednesday mornings run in parallel with a paediatric urology clinic in order to provide means for easy access to urology advice for nephrologists and vice versa when required.

2011 saw the commencement of a registrar list on Wednesday mornings to provide an opportunity for national grid trainees in paediatric nephrology to gain experience in general nephrology out-patient management over a period of time. The clinic has consultant support from Dr Christian and Lunn.

All consultants, apart from the on-service consultant have a clinic for chronic kidney disease which happens currently on Thursday mornings. The clinics take place in the same out-patient area and are attended by other members of the multi-disciplinary team, allowing patients and their parents to see other professionals as needed. We have recognised recently that these clinics are becoming too busy to work to maximum efficiency and we are currently in the middle of a consultation period to assess the best way to reduce patient numbers on Thursday mornings. Almost certainly this will result in a chronic renal clinic taking place on another day but it is yet to be established whether that would be determined by consultant or type of clinic (e.g. separate transplant and chronic renal failure clinics).

There is a nurse-led wetting clinic on Wednesday afternoons. Until 2011, this had been a monthly clinic focussing on daytime wetting primarily. In 2011, a twice-monthly bed-wetting clinic was established run by Caroline Ward, clinical nurse specialist in paediatric urology. Although nocturnal enuresis is managed mainly through the school nursing service in Nottingham, there remain several points of entry to the service and this clinic was established to provide a service for those children referred to consultant paediatric nephrologists from primary care.

There is a 3-monthly neuropathic bladder clinic with the urology nurses in attendance and a young adult urology clinic, run by Mr Alun Williams and Mr Richard Parkinson (consultant adult urologist) which is held 3-monthly at the City Campus.

a) New patients (359 + 39 DNA)
Overall there has been a reduction in new referrals during 2011. This is offset by the increase in numbers of patients seen in outreach clinics (see below). The reason for the decline is likely to be due the effects of the NICE UTI guidance meaning many less patients require referral for investigation following UTI.

b) Consultant initiated (follow-up) patients (3052 + 527 DNA)

Follow-up numbers have increased sharply since 2010. One factor contributing to this is the recent large increase in numbers of patients receiving renal transplants – 20 in 2010 and 22 in 2011. As transplant patients are seen at least weekly for the first 3 months post-transplant, this has generated a large number of additional appointments at the Thursday morning clinics.

A renal endocrine clinic takes place 6-monthly on Friday afternoons. Most patients are chronic renal patients with endocrine problems such as short stature (for consideration for growth hormone) or delayed puberty. The clinic is run by Dr Martin Christian with Dr Tabitha Randell (consultant paediatric endocrinologist).

Patients seen in 2011, broken down into those seen in general, chronic renal and renal-endocrine clinics are shown in the table.

<table>
<thead>
<tr>
<th></th>
<th>New</th>
<th>Follow-up</th>
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<tr>
<td>General clinics</td>
<td>297</td>
<td>1120</td>
</tr>
<tr>
<td>Chronic clinics</td>
<td>60</td>
<td>1909</td>
</tr>
<tr>
<td>Renal endocrine clinic</td>
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Antenatal Urinary Tract Abnormalities

25 couples were counselled antenatally in the Pregnancy Assessment Centre at QMC or in the clinic after referral from fetal medicine specialists. The antenatal service is led by Dr Meeta Mallik, Dr Farida Hussain and Dr Andrew Lunn in conjunction with the Fetal Medicine Consultants.

Children with antenatally detected urinary tract abnormalities are referred from the neonatal service to the paediatric renal unit for postnatal investigation.
**Transition and Transfer Clinics**
Transfer from paediatric to adult renal units only occurs at the end of a process of transition. Within that transition period we aim to offer adolescents the opportunity of a weekend residential holiday focussing on transitioning to adult services. This residential is supported with funding from the BKPA. Our youth service and other staff work with individual adolescents, starting the process when they are in their early teens to ensure they have the competencies required to successfully transition from the paediatric environment to an adult clinic.

In 2011 we strengthened links with Sheffield through meeting up the multi-disciplinary team at the adult unit (led by Dr Sarah Jenkins) to discuss pathways for transitioning. From those meetings, a twice yearly transition clinic and multi-disciplinary discussion meeting were set up in early 2012. Also in early 2012, Dr Meeta Mallik, Sr Kim Helm and Dorro Hackett (renal development youth worker) ran a successful one-day workshop for adolescents and their parents on transition.

There is now a twice yearly transition clinic for Nottingham supported in the adult unit by their young person leads, Drs Charlotte Bebb and Catherine Byrne.

A twice-yearly transition clinic takes place in Leicester. We are beginning to establish separate transition arrangements for the many other adult renal centres where our paediatric patients are transferred to.
REGIONAL SHARED CARE CLINICS

Children and young people are seen the 13 local paediatric centres in paediatric renal outreach clinics. The numbers seen in these clinics, which deliver quality paediatric kidney care as close to home as possible, continue to grow. Over the last 5 years there has been an increase of nearly 50% in the numbers of children seen in these outreach clinics.

<table>
<thead>
<tr>
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<th>2008</th>
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<tr>
<td>Pilgrim</td>
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<td>Lincoln</td>
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<td>King’s Mill</td>
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<td>LRI</td>
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<td>Sheffield</td>
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<td>King’s Lynn</td>
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<td>Norwich</td>
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<td>Addenbrooke’s</td>
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<td>Peterborough</td>
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<td>Rotherham</td>
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<td>Chesterfield</td>
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<tr>
<td>Derby</td>
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<tr>
<td>Kettering</td>
<td></td>
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</tr>
<tr>
<td>Total</td>
<td>642</td>
<td>666</td>
<td>812</td>
<td>831</td>
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TRENT PAEDIATRIC NEPHROLOGY NETWORK

Improving the standard of care of children with kidney disease through paediatric nephrology networks¹ was published by the Royal College of Paediatrics and Child Health (RCPCH) in August 2011 and was the result of a working party between the RCPCH, the British Association of Paediatric Nephrology (BAPN) and NHS Kidney Care. The report was in line with other recent RCPCH strategy to promote good specialised paediatric clinical care via networks. Recommendations made for service improvement were in line with principles within the Kennedy Report of 2010 for children to receive “the best possible quality of care as close to where they live as possible”.

Many of the specific commissioner and provider specific standards are already in place in the Nottingham network: there is already collaborative working with paediatric urologists, good working relationships with local paediatricians and well-developed (though not yet universal) outreach clinics. Another important standard in the document is an educational infrastructure. In 2011, we organised an educational day that combined high quality talks from invited speakers, local consultants contributing to the educational aspect of the meeting, case presentations from trainees and a business meeting for the network.

The programme for the day is shown below:

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker/Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>09:00 – 09:25</td>
<td>Coffee and Registration</td>
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<tr>
<td>09:25 - 09:30</td>
<td>Introduction</td>
<td></td>
</tr>
<tr>
<td>09:30 - 10:00</td>
<td>Fluid and Electrolyte Homeostasis</td>
<td>Dr Martin Christian Consultant Paediatric Nephrologist, Nottingham Children’s Hospital</td>
</tr>
<tr>
<td>10:00 – 11:00</td>
<td>Hypokalaemia and hyperka</td>
<td>Dr Rodney Gilbert Consultant Paediatric Nephrologist, Southampton University Hospitals NHS Trust</td>
</tr>
<tr>
<td>11:00 – 11:30</td>
<td>Coffee Break</td>
<td></td>
</tr>
<tr>
<td>11:30– 13:00</td>
<td>Case Presentations</td>
<td></td>
</tr>
<tr>
<td>13:00– 14:00</td>
<td>Lunch</td>
<td></td>
</tr>
<tr>
<td>14:00 – 15:00</td>
<td>Nephrotic Syndrome</td>
<td>Dr Nick Webb Consultant Paediatric Nephrologist, Manchester Children’s Hospital</td>
</tr>
<tr>
<td>15:00- 15:30</td>
<td>Steroid resistant nephrotic syndrome</td>
<td>Dr Meeta Mallik Consultant Paediatric Nephrologist, Nottingham Children’s Hospital</td>
</tr>
<tr>
<td>15:30- 15:45</td>
<td>Nephrotic syndrome – role of the renal nurse</td>
<td>Ms Kate Baker Nephrology Liaison Nurse, Nottingham Children’s Hospital</td>
</tr>
<tr>
<td>15:45- 16:15</td>
<td>Coffee</td>
<td></td>
</tr>
<tr>
<td>16:15- 18:30</td>
<td>Paediatric renal network business meeting</td>
<td>Eastwood Hall, (Additional cost)</td>
</tr>
</tbody>
</table>

Feedback for the educational part of the day was overwhelmingly positive and a further day has been organised for October 2012 with a plan that this should become an annual event.

The business meeting started with a presentation of the RCPCH document on paediatric nephrology networks and an application of that document to needs for the network from Nottingham. Specifically the following were cited as development aims:

- Outreach clinic in every centre
- Development of SPINs (paediatricians with a special interest in nephrology), stronger working links and shared care of more complex patients
- Guidelines/care pathways for all common paediatric renal problems
- Transition pathway in place in all centres
- IT infrastructure to allow accessing blood results and imaging across the network
- All centres taking active role in multi-centre research and audit
It was agreed that there should be a further meeting in a year. The topics suggested for the next meeting were Henoch-Schönlein purpura and chronic kidney disease. As this year’s meeting focussed on nephrotic syndrome, it was agreed that a network-wide guideline for the management of nephrotic syndrome should be chosen as a pilot network guideline, to be written jointly by a paediatric nephrologist and general paediatrician with input from nurses and a patient/parent representative.
A total of 18 patients received haemodialysis as a chronic treatment in 2011 (compared to 29 in 2010 and 23 in 2009).

The number of patient sessions in 2011 was 1684 compared to 2352 in 2010 and 2164 in 2009, representing a 28% overall decrease in the haemodialysis workload.

The age range of children receiving haemodialysis in 2011 was between 2 and 19 years.

We had only one patient aged less than 5 years in 2011 compared to 7 in 2010. This child spent 5 months of the year receiving haemodialysis. Children aged under 5 require more intensive nursing care whilst dialysing and this can add greatly to the workload in the unit.

There was an average of 11.5 patients having haemodialysis treatment per month in 2011 (compared to 16 in 2010)

<table>
<thead>
<tr>
<th>Month</th>
<th>Number of haemo sessions</th>
<th>Number of patients dialysed</th>
</tr>
</thead>
<tbody>
<tr>
<td>January</td>
<td>131</td>
<td>12</td>
</tr>
<tr>
<td>February</td>
<td>114</td>
<td>11</td>
</tr>
<tr>
<td>March</td>
<td>123</td>
<td>10</td>
</tr>
<tr>
<td>April</td>
<td>141</td>
<td>11</td>
</tr>
<tr>
<td>May</td>
<td>141</td>
<td>12</td>
</tr>
<tr>
<td>June</td>
<td>154</td>
<td>11</td>
</tr>
<tr>
<td>July</td>
<td>147</td>
<td>13</td>
</tr>
<tr>
<td>August</td>
<td>173</td>
<td>13</td>
</tr>
<tr>
<td>September</td>
<td>153</td>
<td>12</td>
</tr>
<tr>
<td>October</td>
<td>144</td>
<td>12</td>
</tr>
<tr>
<td>November</td>
<td>133</td>
<td>11</td>
</tr>
<tr>
<td>December</td>
<td>130</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1684</strong></td>
<td><strong>18</strong></td>
</tr>
</tbody>
</table>

Chronic haemodialysis patients received treatment for between 3 weeks and 12 months. Only 6 of the 18 patients remained on haemodialysis for the whole 12 months, indicating the changing nature of the unit and the input required from staff to commence new patients onto the programme.
Haemodialysis Patient Movement

<table>
<thead>
<tr>
<th>New Patients</th>
<th>Haemo for full 12 months.</th>
<th>From PD</th>
<th>To PD</th>
<th>From failed transplant</th>
<th>Successful Transplant</th>
<th>To Adult Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>6</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>1</td>
</tr>
</tbody>
</table>

**Holiday Patients**
The Children’s Haemodialysis unit still offers the reciprocal arrangement to dialyse children from other centres if holidaying within our region. No patients visited the unit for this purpose in 2011.

**Other therapies**
Apheresis treatments further increased in 2011 with 13 patients being treated in the haemo unit for different conditions. These treatments are in addition to the regular haemodialysis workload.

Double filtration plasmapheresis (DFPP) is a therapy which can be used to treat children with a variety of complex conditions. The unit was the first in the UK to use this treatment in children, and we have now been performing treatments regularly for approximately 7 years.

Currently one patient with familial hypercholesterolemia receives this therapy on a weekly basis to maintain their lipid profiles (two patients treated Jan – May). Last year we altered the therapy to ‘Thermo’ DFPP and have seen a sustained improvement in maintaining cholesterol levels within the normal range.

DFPP has also been used in the acute setting for the treatment of immunological conditions, transplant rejection and disease recurrence. The use of DFPP in the treatment of transplant rejection has remained consistent in 2011.

No. of lipid apheresis treatments: 67 (88 in 2010)

No. of treatments for other conditions: 57 (56 in 2010)

**Plasma exchange** is used in the treatment of acute conditions such as haemolytic uraemic syndrome (HUS) and meningococcal sepsis. Again these treatments are carried out by the specialist nursing team in any area they are needed including PICU, PHDU and E17. Often, this therapy needs to be instigated quickly and the on-call renal nurse is often called upon to deliver the treatment at any time of day or night.

The therapy can also be used for the long term treatment of some chronic conditions such as recurrence of primary disease in transplantation.

No. of treatments: 50 (acute and chronic) (44 in 2010)

**Central Venous Lines**
We continue to have a majority of our patients receiving haemodialysis via a central venous line. During 2011 we continued to use Alteplase as our standard lock for all long term CVLs, but after re-auditing its effectiveness we have changed our use to once a week with heparin twice a week Our on-going audit of the central venous lines shows that
this regime has had no detrimental effects on the rate of occlusions and infections; and
the machine flow rates we achieve have remained the same since the change. We continue to audit.

We continued to have a low number of central venous line infections throughout 2011 with only 3 being seen (3 in 2010 and 4 in 2009).

**AV Fistula**
Three patients had formation of an arteriovenous fistula in 2011. One patient with an existing fistula was transferred to the adult unit. No infections or problems were encountered.

**Aims and objectives.**
In 2012, we plan:

- Further development of audit tools to allow analysis of all areas.
- Development of electronic pathway for dialysis.
- Development of dialysis specific information for patients and parents.

Roy Connell
Clinical Nurse Specialist – Dialysis.
Chronic Peritoneal Dialysis

A total of 19 patients received peritoneal dialysis in 2011. This is a dramatic drop in the increasing numbers we had seen over the previous three years; with our highest number of patients (31) seen in 2010. (28 in 2009, 27 in 2008).

Only 2 families were trained to undertake peritoneal dialysis at home during 2011 (both new patients). Again, this is another fall in the numbers seen in the previous three years with 17 in 2010, 8 in 2009 and 14 in 2008. This reduced number can be seen as being responsible for the overall caseload for the year and highlights the changing needs of the PD population.

The caseload was managed by:

- One full time clinical nurse specialist (with 20% HDx commitment)
- One band 6 renal nurse (0.8 WTE with 40% HDx commitment).

**PD Patient movement:**

<table>
<thead>
<tr>
<th>Remain on PD</th>
<th>Changed to Haemo</th>
<th>Transplanted</th>
<th>Taken off PD</th>
<th>Transferred to adult services</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>1</td>
<td>11</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

**Inpatient admissions.**

There was an obvious decrease in inpatient admissions in 2011 with 100 days. This is compared to 212 days in 2010, 170 days in 2009 and 225 days in 2008. Again this can be attributed to the decrease in patient numbers. However, as a comparison between patient numbers and inpatient days, 2011 is our lowest rate since 2004. (5.3 days per patient /year).

**Peritonitis**

11 episodes of peritonitis in 153 patient months were identified in 2011, giving an incidence of 1 in 14 patient months. This is a slight fall in the improvements we had seen in previous years with 1 in 17 for 2010, 1 in 16 for 2009 and 1 in 15 for 2008. Again, we are meeting the recommended Renal Association standard of 1 in 14 patient months.

31% of the PD patients were aged less than 5 years and therefore fall in the higher risk category for infections.

The unit’s 5-year peritonitis rate now stands at 1 in 15 patient months. This is a more accurate reflection of peritonitis rates, which shows that overall we are keeping just above the standard in this area.

**Exit site infections**

Exit site infections have again continued to affect very small numbers of patients with only two being recorded in 2011 (1 in 71 patient months). No changes have been made in this area but again, diligence is encouraged.

**Catheter loss**

A total of 5 catheters were removed or replaced during 2011 compared to 9 in 2010.

- 2 due to infection
- 3 due to altered position.
Community visits
A total of 18 community visits were made throughout 2011, compared to 24 in 2010 and 32 in 2009. The community/outreach side of the service continues to run at a minimum, but with reduced numbers of patients currently on the PD program; it is hoped that this frequency can increase.

Update program
The locality based update visits, commenced in 2009, were reintroduced in 2011 after being put on hold in 2010 due to patient numbers. These visits are seen as an important part of the support and continuing education process for patients and families.

Aims and Objectives
Further progress in reducing the rates of peritonitis remains one of the priorities for the PD program.

Review of peritonitis guidelines.

Introduction of new Homechoice software.

Increased number of update visits.

Roy Connell
Clinical Nurse Specialist.
Transplantation

In 2011 the Unit performed 22 transplants. An increased number on what was already a record number of 20 in 2010. Two transplants failed due to early thrombosis but 20 have been successful.

This is the main reason the dialysis work load has reduced substantially: ten children were transplanted from peritoneal dialysis and eight were on haemodialysis. An additional four patients were transplanted pre-emptively. Of the two transplants that failed, one patient was transplanted pre-emptively and the other was on haemodialysis.

Two patients received a kidney from a living related donor, either from a father or mother. These patients are doing well at present. The source of the donor kidney is shown in the figure below.

This shows that Nottingham has undertaken increasing numbers of deceased donor transplants over the last 4 years. For the last 2 years, Nottingham has performed more deceased donor transplants than any other paediatric renal unit in the UK.

However, the figure also illustrates that the numbers of transplants performed from living donors are low and not increasing. We have one of the lowest rates of living donor transplants at present which is of some concern. The reasons for this are not entirely clear. In July 2011 the transplant team created a drop in evening clinic, so potential donors could drop in for an informal chat. Following further discussion with colleagues in the transplant living donor teams, into 2012 we plan to raise the profile of living donor transplantation through better information including sessions which will allow parents to consider transplantation options in good time before specific planning for dialysis and transplantation conventionally takes place.

The live donor work up is now solely reviewed by the adult living donor transplant team. The Transplant CNS liaises closely with the adult LRD transplant coordinators and meets on a regular basis for transplant meeting. Potential live donors are encouraged to contact the LRD coordinators and this will then instigate a referral to their GP followed by routine blood tests. This process has been simplified and streamlined to remove previous barriers to initiating the work-up process.
During 2011 the population of transplant patients grew so that by the summer we were following a total of 81 transplant patients. Some patients subsequently transferred to adult services: one patient transferred to Bath, four to Nottingham, two to Sheffield and one to Leicester. No one returned to dialysis apart from the two transplants that failed immediately.

The unit strives to pre-emptively transplant as much as possible. The rate of pre-emptive transplantation in 2011 was low but this might be explained by the increase in transplantation generally and the large number of patients who were successfully transplanted from the dialysis pool. The figure shows numbers of pre-emptive transplants over the last 4 years.

There were 20 pre-emptive patients on the national waiting list during 2011. At the end of 2011 there were 16 active on the transplant list and a further 19 waiting to go on the active transplant list.

The transplant clinical nurse specialist (CNS) and transplant nurse continue to contribute to CKD information days, helping families plan for approaching established renal failure. They also took part in a large number of home visits. These visits occur following the CKD day or are for updates or specifically for patients that require a transition visit before going to adult services. Visits are also carried out before Live Donor Transplant to plan around the date of operation. Along with home visits the transplant CNS has visited schools and attended multi-professional team meetings such as team around the child meetings.

With the high level of transplant this year, there has been a high turn over of ward attenders. The CNS supports the medical staff by seeing ward attenders in a nurse led role.

Ward activity has also been high and at times with a reduced number of staff, the specialist nurses continue to support the ward at busy times. Assisting with biopsies and checking medication are number of jobs that the nurses are called to do help with. The transplant nurses remain quite active in attendance at renal clinic. Alongside their roles

![](image)
as transplant nurses, the transplant nurse and CNS cover haemodialysis. This helps the specialist nurse to keep updated and carry out on call duties.

Communication remains a large part of the transplants nurses’ role. Incoming and outgoing calls are a large part of the transplants work load. The introduction of the renal patient pager has shared the workload of patient calls and provided a secure means and improved service by which patients and families can access timely advice and information when needed.

In 2011, we formalised a clinical meeting on Fridays to review patients seen at the previous day’s chronic clinic. The meeting is attended by consultants, nurse and a dietitian when available. All patients seen are reviewed. In addition to a forum to share difficult clinical problems, the meeting functions as a means to communicate treatment plans for individual patients to all members of the teams and to create a clear plan of jobs required to be done. The majority of these jobs are telephoning patients or parents to inform them of dose changes or the need for early repeat blood tests and this workload is taken up mainly by the nurse specialists.

Standard prophylactic immunosuppression for transplant patients continues to be tacrolimus, azathioprine and prednisolone. We have not chosen as yet to adopt the treatment arm of the recent TWIST protocol with its rapid tailoring of corticosteroids by the 5th post-transplant day and the use of mycophenolate from the start. We have however, individualised immunosuppression in many cases where there is an increased risk of rejection and the use of mycophenolate in place of azathioprine is increasing.

From late in 2010, we were one of the first UK transplant units to use Modigraf, a granule preparation of tacrolimus which is packaged in sachets for dissolving in water. This has been a considerable improvement over parents requiring to open tacrolimus capsules and dissolve the contents for children too young to manage to swallow capsules.

In 2011, we began a home delivery service for medication for transplant patients using the homecare company Healthcare at Home. Despite a few initial problems with delivery and dose changes, the service has been well received by most families who no longer need to phone ahead of clinic to arrange for prescriptions to be submitted to the hospital pharmacy for them to collect in clinic.

Into 2012, we plan to audit our currently policy of managing CMV disease post-transplant through surveillance and pre-emptive management. We plan to review all our current transplant guidelines and we are in discussion about participating in another international multi-centre study of immunosuppression. We wish to develop the concept of a transplant annual review clinic. We also hope to build on experience from our local adult transplant unit to participate in the national paired exchanged programme and to develop our own protocols for transplanting ABO incompatible donation or highly sensitised patient increasing access to transplantation for those children who are likely to have long waits on the conventional national waiting list.

Kim Helm – Transplant Clinical Nurse Specialist
Kate Baker – Staff Nurse
Martin Christian - Lead Consultant for Transplantation
In 2011 a total of over £34,000 was raised for the Kinder Fund. This was almost exclusively raised through the efforts of families of children who have been treated at the Renal Unit of Nottingham Children’s Hospital, along with their friends and relatives. We are grateful for all these donations, big and small and we endeavour to use it all towards supporting the care of children affected with kidney disease.

The aims of the Kinder Fund are to support research, education and psychosocial care of children with kidney disease. In 2011, the charity supported renal nurses attending their annual conference and one of the dietitians attending the European Society for Paediatric Nephrology annual meeting.

In 2011, Nottingham was honoured to be the host for the 42nd EWOPA meeting (European Working group for the Psychosocial Aspects of children with renal failure) and the costs of this meeting were supported by a grant from Kinder. EWOPA is a long-established multi-professional meeting attended by psychologists, social workers, renal nurses, doctors, teachers, play specialists, youth workers etc. At the 2011 conference the theme was working across boundaries. Rosemary Macri of the BKPA spoke about the important role of the charitable sector and Dr Donal O’Donoghue, National Director for Kidney Care, spoke on transitioning young people to adult services. More on EWOPA can be found on the website www.ewopa-renalchild.com.

Kinder supported the commissioning of artwork again in 2011 for the corridor outside ward E17. I am sure you will agree that this beautiful mural of Nottingham’s Goose Fair brightens up the corridor and helps distract stressed children coming into hospital.

Over the years, Kinder has supported the development and printing of literature to give information to parents and to support children through individual kidney conditions and specific procedures. Last year we re-printed the diaries we give to record urine dipstick results for children with nephrotic syndrome and the printing costs of this were met by a grant from Kinder.
Finally, an important aspect of Kinder's support is psychosocial care in all its forms. Several residential holidays run each summer and the Center Parcs trip, aimed mainly for children and young people on haemodialysis is supported by Kinder.

The charity accounts for 2011 are below. The balance on the account remains considerable. Most of these funds are currently ring-fenced towards supporting the development of much-needed day case facilities within the unit. Hopefully 2012 will see some developments on this front. Thank you all for your support!

Martin Christian
Lead Consultant for Paediatric Nephrology
February 2012

<table>
<thead>
<tr>
<th>Date</th>
<th>Details</th>
<th>Amount</th>
<th>Date</th>
<th>Details</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>January 2011</td>
<td>Individual donations</td>
<td>£ 447.91</td>
<td>03/02/2011</td>
<td>Nephrology nurses conference</td>
<td>£ 400.00</td>
</tr>
<tr>
<td>Feb/March 2011</td>
<td>Individual donations</td>
<td>£ 1,780.01</td>
<td>17/03/2011</td>
<td>Doppler and probe</td>
<td>£ 384.30</td>
</tr>
<tr>
<td>April - June 2011</td>
<td>Individual donations</td>
<td>£ 7,002.91</td>
<td>19/05/2011</td>
<td>Unit Time-Out Day</td>
<td>£ 510.00</td>
</tr>
<tr>
<td>July/August 2011</td>
<td>Individual donations</td>
<td>£ 3,796.64</td>
<td>22/08/2011</td>
<td>Swee Pea Mural for ward outside E17</td>
<td>£ 800.00</td>
</tr>
<tr>
<td>Sept.- Dec 2011</td>
<td>Individual donations</td>
<td>£ 636.66</td>
<td>21/11/2011</td>
<td>Center Parcs holiday for children on haemodialysis</td>
<td>£ 1,290.00</td>
</tr>
<tr>
<td>Oct.- Dec 2011</td>
<td>Individual donations</td>
<td>£ 20,043.72</td>
<td>21/01/2012</td>
<td>Reclining chair for haemodialysis</td>
<td>£ 1,781.62</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>17/10/2011</td>
<td>Conference support for diatitian attending ENP</td>
<td>£ 681.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>27/11/2011</td>
<td>Support towards ENP/PA conference</td>
<td>£ 4,200.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>05/12/2011</td>
<td>Printing of nephrotic syndrome diaries</td>
<td>£ 654.00</td>
</tr>
<tr>
<td>Total income for 2011</td>
<td></td>
<td>£ 34,536.95</td>
<td>Total expenditure for 2011</td>
<td>£ 11,136.52</td>
<td></td>
</tr>
</tbody>
</table>

Account balance as of 31/12/11: £ 153,771.45
RESEARCH

Research is an essential part of our work as we seek to “carry out research on clinical care and implement new scientific knowledge to maintain the unit at the leading edge of paediatric renal and urology care” as stated in our mission statement.

This is in line with the vision of the hospital that seeks to foster “a culture in which research and innovation are embedded in routine clinical practice and the creation of an environment in which research findings lead to sustained improvements in the quality of patient care.”

The hope is that in the future all children across the U.K. with chronic kidney disease, needing dialysis or a renal transplant are offered the opportunity to participate in research and we are working with the British Association for Paediatric Nephrology (BAPN) and the Medicines for Children Research Network (MCRN) Clinical Studies Group towards this end.

Funding for research has become more centralised hence more of the studies we are participating in are multi-centred and nationally funded. We are significant contributors to these trials and are currently the leading recruiting region to PREDNOS, a trial into the length of initial steroid therapy in Nephrotic syndrome and the second leading recruiting centre to RADAR, a rare disease registry which is likely to be the basis for many of the future research developments in the U.K.

The result of the changes in national funding is that less funding is available for locally instigated studies. We are still looking for opportunities to perform local trials where possible and have recently completed a study into Urinary Tract Infection in childhood which is being presented at the Annual Meeting of the Royal College of Paediatrics and Child Health.

In conclusion we remain active in research, mainly participating in nationally funded multi-centre studies. In the next year we hope to appoint a research nurse in order to improve our already good recruitment record.

Andy Lunn
Lead Consultant for Research

A summary of our current trials is as follows:

Table 1 – Industry funded trials

<table>
<thead>
<tr>
<th>Trial Name</th>
<th>Summary</th>
<th>Collaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Takeda Trial</td>
<td>Pharmacokinetic trial of antihypertensive medication.</td>
<td>MCRN Takeda</td>
</tr>
<tr>
<td>Cinacalcet trial</td>
<td>Pharmacokinetic trial of a treatment for hyperparathyroidism in dialysis patients</td>
<td>MCRN Amgen</td>
</tr>
</tbody>
</table>
### Table 2 – Nationally funded trials

<table>
<thead>
<tr>
<th>Trial Name</th>
<th>Synopsis</th>
<th>Collaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td>RADAR – Steroid Resistant Nephrotic Syndrome</td>
<td>Registry trial linking genetic tests and outcome measures.</td>
<td>MCRN BAPN</td>
</tr>
<tr>
<td>RADAR – Membranoproliferative Glomerulonephritis</td>
<td>Registry trial linking genetic tests and outcome measures.</td>
<td>Trent Local Clinical Research Network BAPN</td>
</tr>
<tr>
<td>PREDNOS</td>
<td>A double blind, randomised controlled trial comparing a short versus long course of steroids for the initial treatment of nephrotic syndrome</td>
<td>BAPN MCRN</td>
</tr>
<tr>
<td>Quality of Life Study</td>
<td>Evaluating the quality of life in children with Chronic Kidney Disease (CKD)</td>
<td>Psychology Multicentre national trial</td>
</tr>
<tr>
<td>TWIST follow up study</td>
<td>Long term follow-up of RCT comparing early steroid withdrawl to standard steroid based immunosuppressive regimes</td>
<td>Multicentre international trial</td>
</tr>
<tr>
<td>STEPP</td>
<td>Interview based research looking at the transition process to adult services</td>
<td>Multicentre national trial</td>
</tr>
</tbody>
</table>

### Table 3 – Locally Funded studies

<table>
<thead>
<tr>
<th>Trial Name</th>
<th>Summary</th>
<th>Collaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td>CUTIS – Childhood Urinary Tract Infection Study</td>
<td>Evaluating the NICE guideline for investigation following UTI in children under 5 years of age</td>
<td>Microbiology Radiology General Paediatrics Local Funding</td>
</tr>
</tbody>
</table>

### Table 4 – Registry based studies

<table>
<thead>
<tr>
<th>Trial Name</th>
<th>Summary</th>
<th>Collaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td>MCDK Registry</td>
<td>Network-wide registry of patients with MCDK evaluating long term outcomes</td>
<td>Local Network</td>
</tr>
<tr>
<td>Antenatal Registry</td>
<td>Local registry of patients with Antenatal Urinary Tract Abnormalities evaluating the aetiology and outcomes</td>
<td></td>
</tr>
<tr>
<td>International Peritoneal Dialysis Registry</td>
<td>An international registry of outcomes and complications of patients on peritoneal dialysis.</td>
<td>Multicentre International Registry</td>
</tr>
<tr>
<td>Renal Registry</td>
<td>A mandatory national registry of patients (adult and children) with advanced chronic kidney disease.</td>
<td>BAPN and Renal Association</td>
</tr>
</tbody>
</table>
PUBLICATIONS IN 2011


K.J. van Stralen, L, Krischock, F, Schaefer, E, Verrina, J.W. Groothoff, J Evans et al. Prevalence and Predictors of Sub-target Hb level in Children on Dialysis. accepted for publication 2012 - NDT.


Lindley RM, Williams AR, Fraser N, Shenoy MU. Synchronous laparoscopic-assisted percutaneous endoscopic gastrostomy and peritoneal dialysis catheter placement is a valid alternative to open surgery. BJ Pediatr Urol 2011 Oct 22. [Epub ahead of print]


Watson AR, Warady BA. Transition from pediatric to adult centred care. Dial Transpl 2011;156-158. DOI:10.1002/dat:20557

CONFERENCE AND PRESENTATIONS

Conference Presentations
Shenoy, MU. Synchronous Laparoscopic assisted PEG & PD catheter placement is a valid alternative to open surgery, BAPS meeting, Belfast, July 2011

Shenoy, MU. Foreskin reconstruction in Hypospadias repair, IV World Congress on Hypospadias & DSD, September 2011, London

Conference Poster Presentations
The effectiveness of treatment strategies for hypertension in a paediatric haemodialysis population. Lunn A, Harvey E, Geary D. World Congress of Nephrology 2011.

Invited Lectures


Evans, JH. Medical aspects of obstructive uropathy. 6th Annual Paediatric Nephrouroradiology Symposium, Nottingham, March 2011.


Mallik, M. Principles of CRRT and Tumour Lysis Syndrome - Sheffield CRRT course May 2011


Shenoy, MU. Indications for intervention and technical aspects. 6th Annual Paediatric Nephrouroradiology Symposium, Nottingham, March 2011

Watson AR. Transition from pediatric to adult centered care. NKF, Las Vegas, USA. April 2011

Watson AR. Ethical dilemmas in nephrology practice. NKF, Las Vegas, USA. April 2011

Watson AR. Ethics. EWOPA, May 2011.

Watson AR. Successful transition to adult care. 6th Congress of International Pediatric Transplant Association, Montreal, Canada. 25-28 June 2011

Watson AR. Transition from paediatric to adult centred care – where have we got to? Toronto Hospital for Sick Children, Canada. 28 June 2011
Watson AR. The role of APD in pediatrics and long term outcomes. Iranian Society of Pediatric Nephrology, Mashhad, Iran. 20-22 July 2011

Watson AR. 25 year experience of CPD and the choice of therapy. Iranian Society of Pediatric Nephrology, Mashhad, Iran. 20-22 July 2011

Watson AR. Do we always have to dialyse? Ethical dilemmas in the newborn period. Stockholm, October 2011.

Watson AR. Haemodialysis and blood borne viral infections. 5th PAPNA Congress. Beirut October 2011.

Watson AR. Transition from pediatric to adult care. 5th PAPNA Congress. Beirut October 2011.

Watson AR. The best protocol for UTI. 9th Congress of Alanpe, Sao Paulo, Brazil. 27-28 October 2011.

Watson AR. Transition from pediatric to adult care. 9th Congress of Alanpe, Sao Paulo, Brazil. 27-28 October 2011.


Meetings Chaired
Shenoy, MU. for the session on “Distal Hypospadias techniques”, IV World Congress on Hypospadias & DSD, September 2011, London
Conferences & Meetings Organised

Nottingham Children’s Renal and Urology Unit was proud to be the host and organisers for the 42nd annual meeting of the European Working Group on the Psychosocial Aspects of Chronic Renal Failure in Children. The meeting was hosted at Eastwood Hall and though less well attended than anticipated, it attracted delegates from all disciplines (medical, nursing, psychology, social work, teachers, youth workers and play specialists) from countries across Europe.

The theme of the meeting was working across boundaries. The quality of the presentations was high and the debate was stimulating.

There was strong representation from the local team amongst the presentations given. The programme is shown below:

Thursday 5th May

1500-1600  Registration and afternoon tea
1600-1615  Opening and welcome
Dr. Martin Christian, Consultant Paediatric Nephrologist, Nottingham
1615-1630  Swiss Paediatric Renal Registry 1970-2010
Dr. G. Sparta, University Children’s Hospital, Zurich
1630-1645  Job-related Integration for Adolescents with Chronic Renal Failure
Beatrice Schnarwyler, University Children’s Hospital, Zurich

Friday 6th May

0900-0945  Opening Address
Dr. Donal O’Donoghue, National Clinical Director for Kidney Care
0945-1100  Coping With Stress in Parents of Children after Renal Transplantation
Bc. Lucie Kukackova and Mgr. Zuzana Kocabova, Prague, Czech Republic

Qualitative Data from the GCQ Project
Dr. Katherine Hayes, Newcastle, UK

“It is life threatening but I don’t mind”. A Qualitative Study Exploring Young People’s Experiences of Renal Replacement Therapies.
Francesca Wells, Nottingham, UK

1100-1130  Coffee break
1130-1200  The British Kidney Patient Association,
Rosemary Macri, Chief Executive Officer
1200-1300  Working Together
Working together - Making things happen
Ki Lindqvist, Helsinki, Finland

Practical Tools…….Sharing Knowledge
Aline Kalisvaart, Utrecht, Netherlands

Practice Standards for Paediatric Renal Social Workers
Suzanne Batte, Nottingham, UK
1300-1400  Lunch

1400-1430  Developments in Transplantation
Mr Richard Bowen, Transplant Co-ordinator, given on behalf of Mr. Keith Rigg,
Transplant Surgeon, Nottingham

1430-1500  Team Working in Nottingham – An Evaluative Study
Shelley Jepson, Nottingham, UK

1500-1530  Working Together in Europe
Dot Mackinlay, Heidi Steward, Nottingham, UK

1530-1600  Tea and Group Work

1600-1630  Feedback from Group Session

Saturday 7th May

0900-1000  Keynote Speech
Professor Alan R. Watson, Nottingham UK

1000-1100  Feeding Group – Support for Parents
Pearl Pugh, Nottingham, UK

  Painful Procedures
  DVD Presentation, Nottingham, UK

  Addressing the Needs of Young People who Transfer to Adult Renal Services
  Matt Tomlin, Nottingham, UK

  Novel Ways to Improve Dietetic Adherence
  Pearl Pugh, Nottingham, UK
BOOKLETS AND LEAFLETS

**Booklets** (distributed nationally and abroad)
- Kidney Transplantation in Childhood. 1993, Revised 2007
- Sharon Has a Very Important Test, 1994
- Darren Has a Very Important Test, 1994
- Mary Has a Mag 3 Scan, 1994, Revised 2008
- Arnold Goes for a DMSA Scan, 1994
- Why Annie Needs a Blood Test, 1994
- Arnold Has an Ultrasound, 1994, Revised 2006
- Graham Has a GFR Test, 1994
- Rebecca Has a Renal Biopsy, 1994
- Brian Has Bladder Pressure Studies, 1999, Revised 2008
- Dietary Advice for Children on Dialysis, 1997

**Leaflets:**
- Chronic Renal Failure: Tests
- Urinary Tract Infection in Children
- Kidney and Bladder Problems Detected Before Birth by Ultrasound, Revised 2008
- Multicystic Dysplastic Kidney (MCDK) Explained Revised 2010
- A Guide to Childhood Nephritis 2010
- Haemolytic Uraemic Syndrome
- Daytime Wetting: Advice for Children and Parents/Carers 2008
- Posterior Urethral Valves 2010
- Warts and Kidney Disease 2010

**Patient Information** (published in British Journal of Renal Medicine)
- Watson AR. What I tell parents about childhood nephrotic syndrome, 1998
- Watson AR. What I tell parents about UTIs and reflux in children, 1999
- Nevard C. What I tell parents about HUS syndrome, 2000
- Watson A. What I tell families about a kidney biopsy in children, 2002
- Watson A. What I tell families about kidney and bladder problems detected before birth 2003
- Hewson D. What I tell families about haemodialysis in children. 2003

**Videos**
- Supplementary Feeding by Tube
- Feeding by Gastrostomy
- Haemodialysis
- Continuous Cycling Peritoneal Dialysis
- Painful Procedures: Helping Children to Cope, 1995
- Nephrotic Syndrome in Children, 1995

**CDRom**
- Boss of my Bladder

**DVD**
- Moving On (transition issues), 2006

Several of these booklets have been made accessible on the National Kidney Federation website ([www.nkf.org.uk](http://www.nkf.org.uk)) with our permission and also on our own website ([www.childrenskidneynottingham.nhs.uk](http://www.childrenskidneynottingham.nhs.uk))
Appendix 1

**Nottingham and Trent Paediatric Renal Dietetic Service**

The dietetic service provided to the paediatric renal unit during 2011 was staffed from the 1st January to 26th May by Alison Tooke working 1.0 WTE (band 6) and Pearl Pugh working 0.7 WTE (band 7) (Total 1.7 WTE). From 26th May the service was staffed solely by Pearl Pugh (0.7 WTE), until 8th August when Emma Kelly joined the team working 1.0 WTE (band 6) (Total 1.7 WTE 8th August – 8th November). From November 8th to December 31st the service was staffed by Emma Kelly working 1.0 WTE with the support of a Dietetic Assistant 0.72 WTE (band 3).

The Children and Young People’s Renal unit is based at Queens Medical Centre. There are five Consultant Paediatric Nephrologists.

During the year paediatric activity by the renal dieticians amounted to **1540 contacts** compared to **1765 contacts** in 2010.

**Paediatric Dietetic Activity**

Total Number of renal patients requiring dietetic input = **187**

Total dietetic activity = **1540**

The total number of dietetic contacts during 2011 decreased by 12.7% from 2010. This is likely to be due to decreased dietetic staffing levels compared to previous years.

Total number of new renal patients = **76**

The mean number of contacts per renal patient in 2011 was **8.24** which compares to **7.9** in 2010.

<table>
<thead>
<tr>
<th>Treatment</th>
<th>No. of patients 2011</th>
<th>No. of patients 2010</th>
<th>No. of patients 2009</th>
<th>No. of patients 2008</th>
<th>No. of patients 2006</th>
<th>No. of Patients 2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transplant</td>
<td>22</td>
<td>20</td>
<td>13</td>
<td>13</td>
<td>13</td>
<td>7</td>
</tr>
<tr>
<td>CCPD</td>
<td>18</td>
<td>31 (13)</td>
<td>23</td>
<td>27</td>
<td>23</td>
<td>8</td>
</tr>
<tr>
<td>HD</td>
<td>13</td>
<td>29</td>
<td>23</td>
<td>15</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>AKI</td>
<td>18</td>
<td>40</td>
<td>37</td>
<td>21</td>
<td>25</td>
<td>23</td>
</tr>
</tbody>
</table>

(The number in brackets represents the number of new patients starting PD).
Outpatient Activity at Nottingham University Hospital
The CKD clinic takes place on a Thursday morning. Only urgent referrals were seen in the Tuesday and Wednesday nephrology clinics.

Regional Shared Care Clinics
During periods of full staffing a Dietitian attends outreach clinics with the Consultant at both Leicester and Cambridge; these have been identified as a priority for input. Telephone contact was available for all shared care clinics throughout the year.

Clinical renal patient contacts at NUH

Direct and indirect clinical contacts in 2011 compared with previous years.

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<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Inpatients</td>
<td>706</td>
<td>638</td>
<td>703</td>
<td>1051</td>
<td>678</td>
<td>661</td>
<td>771</td>
<td>764</td>
<td>768</td>
<td>628</td>
</tr>
<tr>
<td>Outpatients</td>
<td>817</td>
<td>628</td>
<td>644</td>
<td>468</td>
<td>411</td>
<td>333</td>
<td>447</td>
<td>366</td>
<td>376</td>
<td>488</td>
</tr>
<tr>
<td>Day cases</td>
<td>45</td>
<td>25</td>
<td>82</td>
<td>170</td>
<td>119</td>
<td>111</td>
<td>61</td>
<td>178</td>
<td>190</td>
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<tr>
<td>Home/school visits</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>6</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
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<td>0</td>
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<tr>
<td>Telephone</td>
<td>224</td>
<td>229</td>
<td>218</td>
<td>309</td>
<td>470</td>
<td>330</td>
<td>394</td>
<td>423</td>
<td>430</td>
<td>424</td>
</tr>
</tbody>
</table>

Inpatient contacts also include indirect contact with health care professionals.

*Outpatient contacts include contact with patients attending clinic and those reviewed on haemodialysis
**Patient Activity**
The total number of dietetic contacts during 2011 decreased by 12.7% from 2010, which reflects periods of reduced staffing. Total inpatient and outpatient dietetic contacts have decreased slightly to 73% of total dietetic contacts (76% in 2010) while telephone contacts have slightly increased to 27% of total dietetic contacts (24%).

The number of contacts made to HDU/PICU in 2011 was 46, which also remained consistent to 2010 (50 contacts in 2010). This partly reflects the increased numbers of renal transplants as these patients generally transfer to PHDU and PICU immediately post transplant.

**Nutritional Support**

### Number of contacts

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
</tr>
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<tbody>
<tr>
<td>Oral calorie supplements (OCS)</td>
<td>306</td>
<td>544</td>
<td>285</td>
<td>390</td>
<td>415</td>
<td>435</td>
<td>456</td>
</tr>
<tr>
<td>Gastrostomy button feeding</td>
<td>426</td>
<td>512</td>
<td>357</td>
<td>375</td>
<td>460</td>
<td>569</td>
<td>387</td>
</tr>
<tr>
<td>NG/NJ tube feeding</td>
<td>157</td>
<td>180</td>
<td>175</td>
<td>225</td>
<td>246</td>
<td>184</td>
<td>319</td>
</tr>
<tr>
<td>PN</td>
<td>2</td>
<td>14</td>
<td>7</td>
<td>38</td>
<td>7</td>
<td>29</td>
<td>4</td>
</tr>
</tbody>
</table>

(OCS - includes Oral Supplements and Nutrient Enriched Infant Formula codes)

Contacts for nutritional support either orally, via a tube or parenteral nutrition (PN) has further increased to 76% of all dietetic contacts during 2011, compared with 69% in 2010 and 65% in 2009. The number of contacts for PN has decreased in 2011 from 2010.

The overall contacts for patients being tube fed in 2011 is 706 compared to 758 in 2010, which is fairly consistent and the decrease again is likely to reflect periods of reduced staffing. From data analysed the total number of contacts for gastrostomy feeds has decreased and nasogastric feeds increased, the reporting of this data maybe slightly
inaccurate with those having gastrostomies placed not always having problem codes changed on clinical manager.

At home during 2011 there was a total of 31 patients with a gastrostomy in situ and 3 patients who received nasogastric tube feeds.

**Abstract/ Publications 2011**
Does dietary energy intake change post renal transplantation? (AL/PP)

**Ongoing research 2011**
Analysed data for TWIST study - assessment of dietary intake 6 and 12 months post renal transplant (PP/AT)
Texting study. A study to improve phosphate compliance in young people on HD, analysed and presented as oral presentation (PP)

**Conference Presentations/Attendance/ Course attendance**
European Society for Paediatric Nephrology Conference, Dubrovnik. September 2011. Presented the TWIST data as a poster.
Gave an oral presentation on ‘Our experience of a feeding support group’ for parents of children with CKD, at European Working Group on Psychosocial Aspects of Children with Chronic renal Failure, conference in Nottingham (PP – May)
Presented the Growth Audit data from 2009/2010, to the renal team
Attended Paediatric Renal Interest Group Meeting in Birmingham (EK –November)

**Teaching**
Teaching newly qualified paediatric renal nurses on E17 (PP/AT)
Teaching PICU nurses from Sheffield (PP)
Teaching sessions on the haemodialysis bay to patients (PP/AT/EK)
Teaching session for registrars and junior doctors – Dietary Management of CKD and AKI (PP/EK)
Involved in dietetic student training (PP/AT/EK)
Set up feeding support group for parents of children with CKD (PP/AT). To run 3 times per year

**Memberships**
Members of the British Dietetic Association (BDA) (AT/PP)
Members of the BDA Paediatric Group (AT/PP)
Members of PRING (2 meetings per year) (AT/PP/EK)

**Innovations/working groups/courses**
Feeding Support Group – organised and led (PP/AT – Feb, June)
Attended Good Clinical Practice training (PP - March)
Easter Cookery session on the haemodialysis unit (SK/AT - April)
Designed scoop chart for infant formulas and Renvela administration (PP/AT)
Ongoing work with catering regarding children’s renal menus at QMC (PP/AT/EK)
Organised a visit to the department for 8 work experience students (PP)
Hosted a dietitian training programme for dietitian from Cambridge (AT/PP)
Updated Phosphate diet sheet (AT)
Updated Eating Out with CKD (AT)
Produced Diet and Steroid induced Diabetes diet sheet (AT)
**Plans/ Targets for 2012**

- To complete annual dietetic assessments involving analysis of 3 day food diary on all dialysis patients
- Continued involvement in teaching of new staff and educating existing members of staff with regard to the renal diet
- Continue to improve menu choices for patients on E17
- Continue to develop and review dietetic resources
- Continue to work on a strategy to improve phosphate compliance in children and young people
- Plans to work with Roxanna Shraft from GOSH on a study titled: Prevalence of hypervitaminosis A and its association with chronic kidney disease

Emma Kelly
Paediatric Renal Dietitian
2011 has been a stimulating and very exciting year within the field of urological nursing, with continued advances in several aspects of our work.

Most noticeable is the introduction of our modernised nocturnal enuresis service which encompasses bladder assessments, nurse led clinics and regular follow up phone calls. This together with the huge reduction in the need for a general anaesthetics for supra pubic insertion of the urodynamics catheter because of the ever increasing use of entonox for this procedure has lead us to believe we have had a very successful year.

The number of children currently requiring our service is:

196 Children with a neuropathic bladder
258 Children with daytime enuresis
94 Young Adults in the Young Persons Clinic

Children’s Outpatient Department
Total number of children seen in clinics by the urology nurses in 2011 was 380, a figure comparable with last year.

As I reported last year the urology nursing service had been increasingly asked to support children with nocturnal enuresis but as this had never been our responsibility it was proving to be very difficult. I discussed this with my manager who was very supportive and together we discussed the best way forward to ensure that these patients received a good quality service and we met the recommendations within the NICE guidelines for Nocturnal Enuresis. We agreed that Caroline Ward who was currently working part time with the Urology Nurses covering maternity leave could continue to work 12 hours a week organizing and developing our enuresis service in the University Hospital. This Caroline agreed to and her new role commenced in September 2011.

The Nocturnal Enuresis clinic for Children and Young people will be accessible to patients by referral from consultants within the acute setting here at the Children’s Hospital. The clinic runs every 1st, 3rd and 5th Wednesday of the month in Children’s Outpatients Clinic South.

In addition to the nurse led clinics Caroline will be carrying out full non invasive bladder assessments on the refractory night time wetters in order to gain a complete and detailed evaluation of the child’s condition. The service will be patient dependant and it is a service vision that as patient number increases the service will develop and be able to offer clinical guidance but also a support infrastructure for Children, Young people and their families with similar concerns.

**Day Case Assessments**
Total number of children requiring day case bladder assessment was 109 which is almost identical to last year figures.

We have, as ever an ongoing huge amount of referrals for this non invasive investigation that often leaves us with a long list of children waiting for the test. This examination is popular as we can obtain quite detailed information about how the child’s bladder functions on a day to day basis which can be very valuable when deciding what the next method of treatment will be. It gives the urology nurses an opportunity to discuss at length
the child’s wetting and toileting pattern, there fluid intake and how generally the family cope with this difficult and embarrassing problem.

**Urodynamics**

Total number of children undergoing this investigation was 80 an increase of 33% from last years figures, as we now carry out this investigation three times a month. This has greatly improved our flexibility and allows us to add urgent cases to the lists without the need to cancel other children already booked.

Last year I introduced the use of entonox when having urethral catheters inserted in the x-ray department. Our aim was to reduce the number of children requiring a supra pubic catheter (SPC) insertion in theatre prior to this investigation. Last year 20 children required SPC insertion this year only 6 children have undergone a general anaesthetic for insertion of this catheter prior to urodynamics. This must have made a huge cost saving for the hospital as well as greatly improving the children’s experience. This improvement has been well accepted by both the children, parents and the staff of this hospital, such that we now also use entonox with some children who have a micturating cystograms and we have administered entonox on 9 of these children.

All four of our urology nurses are now qualified to administer Entonox and we very much hope to be able to train some of the radiography team how to administer this in order that it can be used even more successfully in this department.

Finally after many, many months of deliberation with infection control we now have a programme in place to sterilize the catheters we use for Ambulatory Urodynamics. So it is hope that we will be able to offer this investigation as a method of diagnosis in the future.

**Clean Intermittent Catheterisation**

66 children / parents, were taught clean intermittent catheterisation, an increase of 88% since 2010 plus a further 38 children were brought into hospital for their supra pubic catheter changes which makes an increase of 26% on 2010 figures.

**Community**

We have carried out 34 home and school visits a figure which is an increase of 36% from last year’s numbers. We continue to follow the agreement set that only essential home/school visits should be carried out and when possible we have asked parents/carers and schools to travel in to hospital to see us for teaching, training and other advice.

**Telephone Calls**

The service made
1613 calls to parents
191 calls to health care workers
189 calls to schools

Overall total 1993 calls made/received by this service

**Other Areas of development**

We have recently put together a case of need for an Urostym Pelvic Floor Biofeedback machine.

Day and night time wetting in children leading to incontinence is an extremely common condition treated within the paediatric setting. It is estimated that 500,000 5-16 years old children wet the bed of which 10-28% also have day time problems.
The children who would benefit from this form of treatment are children with dysfunctional voiding (DV). This means at the very time the child’s sphincter and pelvic floor should be relaxed to enable the child to void completely it is contracting and not allowing a free flow of urine and complete emptying of the bladder.

Pelvic floor relaxation using biofeedback has been successfully implemented in both adults and children. The electromyography (EMG) measures actual muscular activity with anal and vaginal EMG surface patches. One of the many reasons this machine as proved to be so popular is that it as a paediatric animation mode which allows children to exercise/relax the correct muscles whilst playing a fun game.

This is patient controlled and an alternative to surgery and/or medication. It ensures that the progress of the child is monitored and the clinician becomes a personal trainer by providing positive reinforcement throughout.

There is no other machine available that as a paediatric package incorporated within its system. Nottingham University Hospital is presently making out of region referrals to Sheffield Children’s Hospital in order that our children can receive this treatment.

Treatment takes 1 hour a week and runs over a 6 week period. Current nursing staff has been identified to carry out this management and a room as been made available where children can undergo their therapy. We believe this will lead to a reduction in the need for repeated outpatient’s appointments.

Treatment can be terminated at any time before the six weeks; success rate is 82-90% - either complete ‘cure’ or improvement.

There are only 3 other centres who have this machine already Sheffield, Liverpool and Great Ormond Street. We believe if Nottingham is to remain at the cutting edge of urological advancements this must be our goal for 2012.

Another area which we have been asked to be involved with is MR Urography and to my knowledge this is a new investigation here in Nottingham and it requires our service as its protocol is quite rigid and needs a named nurse to ensure that all aspects of the test is carried out at the exact time. I am unclear at this moment quite how much additional work this will involve.

Christine Rhodes remains the chairperson for the RCN Children’s Urology Continence Community, and continues to work closely with the R.C.N. and she remains the secretary for the European Society for Paediatric Nurses (ESPUN) Christine also works with the Paediatric Continence Forum led by Penny Dobson all of this work being carried out in Christine’s own time.

Christine Rhodes and Gill Young have continued to teach on a wide variety of educational courses, study days and conferences. Please see below.

All of the Urology Nursing team have attended all mandatory training days.

March 4th Chris Rhodes & Gill Young attended Trent Nephrourology Meeting held in Nottingham.
March 7th Chaired the RCN Children’s Urology/Continence Community (PUCSIG) study day in Nottingham.
March 9th Chris attended the Peristeen rectal washout study day in Derby.
April 1st Chris attended the Appraisal Training day here at QMC.
April 15th. Chris trained Derby nurses how to catheterise male patients.
May 10 European Society of Paediatric Urology conference (Copenhagen - Denmark as ESPUN Secretary)
May 10th Renal time out day.
June 7th Gill attended the CAF awareness study day.
June 15th Gill and Emma attended the Peristeen study day in Nottingham.
June 23rd Chris attended a Master class for Peristeen washouts in Manchester.
September 15th Chris spoke at the British Association for Paediatric Urology Nurses in Cambridge. Caroline Ward attended as a delegate.
September 20th Teaching MSc Students at QMC
October 17th Chaired the RCN Children’s Urology/Continence Community (PUCSIG)
November 2nd Chris spoke at the Chesterfield Continence Study day.
November 10 Chris and Gill Young taught on Bladder and Bowel course here in Nottingham.
November 14th Taught on the Child Branch Programme, children with bad bladders
November 30th ESPUN Board meeting in Zurich organising next years conference.

Conclusion
2011 was a very busy year, during which our overall patient numbers have increased for the fourth year running. We will continue to strive to maintain the highest possible standards of care for our urological patients at all times.

Christine Rhodes
CNS Paediatric Urology
Social Work Report

Social Work support to children with chronic kidney disease and their families continues to be provided by Heidi Steward (full-time post) and Suzanne Batte (part-time post). It has been a challenging year due to the decision taken by Nottinghamshire County Council to terminate their employment contracts. Funding for the posts has always been met by NUH with some charitable contribution at times from the British Kidney Patient Association.

Nottinghamshire County Council decided that they could no longer provide contracts for these posts despite the fact that they were not actually funding them. This is due to the specialist nature of the role and the issue of accountability. This resulted in a long period of uncertainty regarding the future of these posts. The decision was initially challenged by the renal team and attempts were made to continue with the same working arrangement. Social workers are not generally employed by health and local authorities are usually best placed to ensure that the professional role is supported and protected through supervision and appropriate training.

The posts have subsequently been transferred over to NUH and arrangements have been made to provide supervision by an experienced social work team manager. Despite great uncertainty and anxiety regarding the future of the renal social work service, it has survived and continues to be an integral part of the support offered by the Paediatric Renal Team.

Chronic kidney disease is a life-long condition which has complex psychosocial implications for the child and other family members which requires long term support. We are committed to providing a high standard of psychosocial care to children with chronic kidney disease and their families through traditional social casework and counselling skills. We aim to provide emotional support as well as offering practical and financial assistance such as advice regarding benefit entitlements and also by applying to charities.

An important part of our role is to visit families at home as this allows time and space away from the clinical setting to discuss worries and concerns. In particular, parents who are caring for children on peritoneal dialysis at home can feel isolated and they can become exhausted due to the daily demands of the treatment.

Home visits are often welcomed by families at critical stages in the treatment process. The diagnosis stage is often very difficult and children and families need support to come to terms with an uncertain future. Visits are made prior to a child starting dialysis as well when they are due to go on the transplant list. We also visit parents who are interested in becoming live kidney donors. Most of these visits are undertaken with our renal nursing colleagues but we sometimes visit families independently if they require additional support.

Social work support is also offered to acute patients attending the renal unit. The sudden onset of a serious illness can be very worrying for a child and their family particularly if the child requires acute dialysis. These families often live some considerable distance from the renal unit which impacts on managing childcare for siblings as well the parents’ employment. We try to alleviate some of this stress by giving appropriate advice and sometimes applications are made to charitable organisations for financial assistance. We also advise families to contact us following discharge as sometimes there is delayed shock and anxiety regarding the trauma associated with sudden acute illnesses.
The following provides some information regarding social work activity during the last year:

- 44 home visits were made in total
- 4 child protection case conferences were attended
- 18 Team Around the Child/ multi-disciplinary meetings attended
- 4 school visits

National Links
We continue to maintain close links with other renal social workers across the country through the BASW Renal Special Interest Group. Heidi also attended the annual training day. This annual event encourages renal social workers to share good practice via presentations and outside speakers are also invited to provide relevant training.

Conferences
The annual EWOPA conference was held in Nottingham this year at Eastwood Hall and delegates from other children’s renal unit in the UK and Europe attended. This unique conference is dedicated to looking at the psychosocial impact of chronic kidney disease on children and their families. The conference has been in existence for over forty years and Nottingham hosted the event for the first time.

Heidi presented a paper at this conference about trying to secure European funding for psychosocial research projects that could potentially be undertaken jointly with other renal units.

Suzanne presented a paper at this conference regarding practice standards for renal social workers.

Suzanne Batte
Paediatric Renal Social Worker
EDUCATION

2011 has been a very busy year for us, catering for a changing population in the Dialysis Unit and on E17.

The teachers working on E17 were John Young and Trevor Gard, whilst the Dialysis Unit teachers during the year were Elaine Boon, Kate Lawes and Carol Lindsay. Two Teaching Assistants, Jonathan Gray and Denise Cross also provide essential support in the Dialysis Unit. We have had a weekly volunteer, Janet Wilson, who assists with music activities. We are helped from time to time by other volunteers and students. In July we were sad to see Elaine Boon leave the unit, taking early retirement. She had been with the unit for many years and will be missed by patients and staff alike.

Education is provided for all school-age children on the ward, either by the bedside or in the small classroom, or whilst receiving haemodialysis. In the very busy Dialysis Unit 24 children were taught for varying lengths of time whilst having treatment.

### KEY STAGE CHRONIC HAEMODIALYSIS

<table>
<thead>
<tr>
<th>KEY STAGE</th>
<th>CHRONIC HAEMODIALYSIS</th>
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- GCSEs – pupils have been able to undertake exams whilst having haemodialysis although we generally liaise with school and dialysis staff to allow pupils to take exams at their own schools wherever possible.
- Depending upon dialysis schedules, pupils attend the Hospital School on either two or three days per school week. The intervening days are spent at their home school. This means that for many pupils the majority of their schooling is with us.
- Liaison continues to be a key area of the Hospital School's work. Every attempt is made to ensure that there is close liaison between the Hospital School and the home school in order to minimise the disruption to education that could be experienced by our renal pupils. The liaison is achieved by:
  - Regular telephone/ email contact with the schools of our long-stay pupils, requesting curriculum work, thus ensuring continuity of education.
  - Termly reports are sent to schools and parents of haemodialysis patients to inform them of work carried out and progress made whilst in hospital.
  - Short reports are sent to schools when a pupil has been with us for two weeks or more on the ward.
  - Requests for curriculum information from the home school are made for our haemodialysis pupils.
  - For our chronic renal pupils who have received regular education input from the Hospital School throughout the academic year we request SATs and GCSE results. These, along with the school feedback forms, allow us to evaluate our input ensuring that we provide appropriate child-centred support which builds on best practice.

- Review meetings are attended where possible.
- Telephone contact is maintained with a range of partners who provide support for our pupils: Home Education, Examination Boards, School Examination
Officers, Education Welfare Officers and FE Colleges are involved as and when appropriate.
- Weekly multi-disciplinary, psycho-social meetings are attended where the wider needs and issues of patients are discussed by the Renal team.
- The Renal Time-Out day was attended by two of the teachers.
- One teacher attends the weekly renal outpatient clinic, making contact with children and young people and helping with school or college issues or problems.

**Educational and other activities include:**
- Arranging home tuition for supplementary education or to support reintegration on return to school.
- Languages Day, when children and staff joined in a day of activities, food and fun with a language theme.
- Weekly music sessions for pupils on the dialysis unit and within our main school for those who are able to leave the ward.
- We recognise the paramount importance of the children keeping up with their schoolwork but we also try to make their time in school enjoyable and therefore fit in organised “fun” activities such as cooking, murder mysteries, plays and art. We even put on a panto in December!

Recognising the importance of keeping to a Renal diet we regularly focus work on healthy eating and are collaborating with the Renal Youth Worker in arranging cooking sessions in the Dialysis Unit. This will contribute towards a Youth Achievement Award, for our older students.

This year, within the Renal Team, we have been involved in negotiating dialysis times of the secondary pupils to fit in with lesson and exam timetables in mainstream schools, thus helping to maximise the quality time there.

We continue to look forward to promoting and enhancing the educational opportunities of our hospitalised children and young people in 2012.

Kate Lawes
Play Specialist Report

E17 is a 10 bedded inpatient ward specialising in renal and urology conditions; although we have taken patients with a wide range of other conditions and needs, which has been very interesting as I have had to learn and understand about this. Along with the inpatients we are kept busy with ward attendees and day case patients, coming in for renal scans, bloods, cannulation, biopsies, stent and line removal etc. Aside from the ward there is the Elizabeth Ward Dialysis Unit which has between 5 and 7 patients a day, 6 days a week. Although these patients are regular attendees and get involved with general play activities, I have also worked with patients in here on diet, transplantation, fistulas and other issues relating to their treatment.

Away from the ward I have been helping to staff the Elective Admissions Lounge (EAL) from March until the end of the year, taking patients from all over the unit to theatre and preparing the patients and families for their operations. This year has also seen a rise in referrals from Consultants, Clinical Nurse Specialists, and Specialist Nurses.

Instances of Contact with Patients:
In 2011 I have had over 2000 instances of contact with patients in all areas that I have worked (ward, dialysis, EAL, clinic, home visits etc) and by various means of interaction from general play to preparation techniques, distraction and specialised play.

Haemodialysis activities:
This year we have been involved in many activities in the dialysis unit, working with the hospital school and youth service as well as nursing staff. Examples include: Haemo’s Got Talent Show, where patients and staff each performed for the trophy. Spooky Halloween Fun where we had a quiz, pin the nose on the pumpkin, trick or treat and a blindfolded touch challenge.

Home visits:
In 2011 I have been on 3 home visits with members of the multiprofessional team.
- One visit was to prepare a young person for Dialysis/ Transplantation, with the renal social worker and Transplant Nurse Specialist. To discuss any issues and talk about being on the list, what the transplant involves, different kinds of dialysis and to talk about how the young person feels all of these things and to answer any questions or concerns that he had.
- One to talk to a 7 year old boy about his kidney disease as he didn’t understand why he had restrictions, medication etc. This boy had only been seen in clinics and was very confused and parents requested some input to explain things to him in an age appropriate way. This visit was very positive and the boy asked lots of questions and said that he was much happier after we spoke.
- The last visit was to see a young boy who has dialysis; this was to discuss a previous failed transplant as he is working towards another, and to discuss his anger and behaviour as a result of this failed transplant.

I have also attended a CAMHS meeting with a young person who was referred through the renal consultant. As I had worked with this patient to prepare her for transplantation, supported her and the family throughout the transplant and post transplant and had built up a good relationship with the family as a whole. The patient had talked to me about issues and felt comfortable talking to me about problems that had arose.
Renal Residential:
The British Kidney Patient Association fund residential holidays for patients so that they can meet other children and young people with Kidney Disease, share experiences, increase self-esteem and independence skills.
In August 9 patients, myself, a nurse and 2 volunteers headed to Fairthorne Manor in Southampton for a 5 day residential funded by the BKPA. The patients were aged 10 to 13 years, some of which had never been away from home before. It was a very positive week of team building, activities, fun and discussions. The group supported and encouraged each other in activities which boosted the confidence of some of the young patients. There was discussion about procedures, treatments and transplants. We also held our own talent show on the last night where everyone took part. It was a fantastic week for the patients and a good break from the routine of medication and hospital for the families. Follow up with the patients involved this year has shown that all have kept in touch and have maintained good friendships through this residential.

Projects:
• Visitors: I am the visitor co-ordinator for the Nottingham Children’s Hospital, which involves working with external parties to make their visit to the hospital run as smoothly as possible. This year I have worked on a leaflet with the Communications Department to make visitors aware of the variety of wards and departments that we have and to ensure that everywhere is visited by someone. This role include updating diaries with Angela Horsley, Communications, Parking and Security, Hospital Photography as well as the play team and ward managers and staff.
• Christmas card Project: This year I have worked on a Christmas card project to help raise money for Nottingham Children’s Hospital. This involved getting children and young people on all wards and departments to design Christmas pictures. I enquired about printing and costing and with the support of Stirland Paterson Printers, the project got the go ahead. 8 designs went off to print and went on sale in November which could make the charity up to £800 thanks to Simon Stirland for funding the project for us this year.
• Volunteers: This year we have started taking on Play Staff Volunteers in the Children’s Hospital, and I have had the opportunity to be involved in writing the role description and outline for up and coming volunteers, as well as supporting them in their induction process.
• National Renal Information: I was put forward by the renal consultants and dialysis nurse manager to be the Nottingham link for the renal information booklets. The children’s renal units around the county are looking at getting information booklets for children and families that are consistent nationally. The project is set to take approximately 2 years with literature being sent for review on a weekly basis. To be discussed with the team and relevant members of the MDT and then fed back.

NUH Honours:
I was fortunate this year to be nominated for the NUH Honours in the category of Family Health and got shortlisted and invited to the awards evening on the 18th November at the East Midlands conference centre. I didn’t win overall; however it was a great honour to be shortlisted and I had a great time on the evening.

Donations:
Many thanks to everyone who has made donations to E17/Dialysis Unit for Play Services over the past year:
• Mystery benefactor - funded an art & craft session in the Dialysis Unit
• Diane & Pete - funded new toys and play equipment
• Sarah Bowden - ran a 10k race and raised over £500
• Kevin Harris & family - raised money to buy 2 portable DVD players and DVD’s
• Jordan Williams and his college class - raised over £180 to buy 2 portable DVD players and DVD’s for children and young people on dialysis.
• Gloria (grandmother of a patient) raised money to buy a flat screen TV and stereo system for the dialysis unit.

Feedback:
Comments taken from the Play Service feedback book:
“Claire is an outstanding member of staff and continuously displays attributes well beyond the values and behaviours expected of staff at NUH. Her efforts are tireless and are always with the thoughts of our paediatric patients and their parents before her own.”
(Taken from the NUH Honours Award Booklet)

Claire Hardy
Play Specialist
Youth Work Report

Youth work starts where young people are – with their own views of their lives, the world and their interests. But it does not end there – youth work is about encouraging young people to think critically about their lives and values, about offering new experiences and challenges, about increasing young people’s abilities and aspirations’ (National Youth Agency, 2007).

From January 2011, 74 different young people with renal conditions and their siblings have had contact with the NUH Youth Service. This could mean advice and support from the youth workers; support on the ward and in clinic; using the Youth Room during hospital stays; attending the weekly hospital youth club; activity and support programs for long-term patients; transition support; and/or becoming involved in long-term projects such as the Youth Achievement Awards, Youth Forum, day trips and residential holidays.

Dialysis Bay:
It has been a busy year in the Dialysis Bay. Young people have taken part in many different events and activities such as movie days, Spooky Halloween Activities, Quizzes, Screen Printing and Heamo Bays got Talent which included singing, comedy and synchronised swimming with out water! Providing activities whilst young people are having treatment is important as it allows young people to interact with each other, try new activities and be distracted from the hospital environment. Developing these relationships whilst having treatment are vital as young people can gain support from their peers which enable them to share knowledge and experiences unique to them.

Youth Achievement Award:
Young people have been able to work towards their Youth Achievement Award whilst having treatment. The YAA is a nationally recognised accreditation that young people can participate in which helps them develop different skills, develop self confidence and work with other young people. The young people have been doing a variety of different activities such as cooking, animation, fundraising and screen printing.

Drop-In Sessions:
The youth service provides daily drop-in sessions for young people to come and use the facilities. I have been able to encourage young people from the renal unit to access this service which has enabled them to have time away from the ward in a non-medical environment. It also allows them to meet other young people in hospital and access support from staff. ‘I love the Youth Room so much! I can get away from it all when I feel swamped by medical stuff and I can just come and chill out.’ (Young Person)

Trips and Residentials:
As well as attending generic youth club trips and residentials, young people also attended renal specific activities such as a week away in the Isle of White and 5 days at Centre Parcs. This has given them the opportunity to meet other young people with long term health conditions, try new activities, develop independence and interests and raise their self esteem. ‘I liked being away from home. I learned lots and lots and was able to think about what I want to do’ (Young Person)

Young people also attended day trips to places such as The Deep, Lego Land, Alton Towers, Clumber Park, Narrow Boat Trip, Wicked in the West End, Drayton Manor Park, Christmas Cinema Trip, Skegness, Bowling and Laser Quest.
Meeting in areas away from the hospital is vital for young people who are often miss out on mainstream activities as it allows them to meet other young people in similar situations and develop peer support in a non-medical environment.

**City Youth Club (CYC):**
City Youth Club (CYC) is open to young people 2 nights a week. Available for young people in the Nottingham area with long term health conditions it is also open to inpatients. They can take part in different activities such as arts and crafts, group games, team-building activities and lots more! "I have met loads of new friends and done stuff I would never imagined I would. Having a chronic condition does not have to hold you back!" (Young Person). This year saw the launch of 1st Story. A project set up to inspire creativity and literacy in schools across the UK has joined up with the NUH Youth Service to offer this project to young people in hospitals. Authors run fun, creative workshops for young people to explore their poetic side and find a new forum in which to discuss their experiences.

**Staying Positive:**
The Staying Positive scheme is set up by the Expert Patient Programme. Young people attend a series of workshops run by other young people with long term health conditions. The workshops focus on areas such as medication taking, bullying, sexual health and relationships and young people are able to share experiences in a safe, young person friendly environment. This year a group of 8 young people took part. One renal patient attended the workshops as a young facilitator and afterwards trained as a young person. This means that he will be able to facilitate workshops in the future. The training he attended is also accredited which he can now add to his CV.

**Fundraising:**
2011 also saw 2 young people complete the British London 10km Run and raised over £200 for the Kinder Appeal. The run is already booked for 2012 with more young people wanting to get involved. 'It’s not about what position you come in but actually doing it that’s important. Showing other people that I can do it!’ is what one of the young people said about taking part. Raising money for their unit was an important exercise as it meant that they could give something back.

**YPFC:**
2010 saw the re-launch of our youth forum Young People for Change. 2011 saw their involvement in the Quality Account Public Survey, Games Development Programme, Complaints Poster for NUH and Transformation of the Hospital Library. The group also had their first annual residential which consisted of various workshops including The Ideal Health Professional, ‘If only we had Jamie’ that sought young people’s views on service improvement following the results of the PICKER Survey. Represented with in this group are 2 renal patients who are able to share their experiences of being in hospital, meet other young people and have their voices heard.

**Home Visits and Chronic Kidney Assessment days:**
This year I have been on 8 home visits. This may be for many different reasons; to introduce transition and transfer to the adult unit; to meet young people; build relationships with them or for general support. This year I have also been working with the wider renal team meeting young people and introducing them to the youth service, what we do and how they can get involved.

**External Work:**
As part of both Youth Services Renal and I have been able to highlight the work undertaken by both areas through teaching sessions with medical and nursing students and transition training and support. I attended the 2nd annual Hospital Based Youth Workers Networking Conference in Wrexham which focused on engaging with young people, developing positive relationships, media stereotypes and positive images. It also included a case study on working with young people in a mental health setting. I supervised a student on work experience from school and a youth service volunteer completing her Youth Work Certificate.
Day trips, residencies, clinic, drop-in sessions, ward-based work and work in the dialysis bay have all provided different opportunities for young people to access support from the youth service. Whether it is through group work or informal discussions young people have been able to experience new things, meet new people, develop self-confidence and challenge themselves in an environment that is both safe and caring.

The numbers of young people with renal conditions accessing the youth service are some of the highest in the service. This shows that having a dedicated youth worker for renal services means that young people can access services that are appropriate for them and gain support from professionals in a non-medical environment.